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<b>13. ABSTRACT (Maximum 200 words)</b> <p>The San Francisco Bay Area is the forefront of alternative medicine practice in the United States. The Bay Area also has many health resources to accommodate ethnic diversity in health access and choices. This study attempts to systematically determine the prevalence and factors influencing the utilization of conventional and nonconventional breast cancer treatments through telephone interviews on approximately 400 breast cancer patients diagnosed between 1990 and 1992 in San Francisco representing four ethnic groups (Whites, Blacks, Hispanics and Chinese).</p> <p>As of August 15, 1995, we have completed 120 interviews and found that nearly half of them have ever used nonconventional therapies after breast cancer diagnoses. Ethnic differences were observed: 49% white, 57% blacks, 70% Hispanic and 38% Chinese have used at least one kind of alternative treatment..</p> <p>Our long range goal is to assess outcomes of various treatment options among these ethnic population</p>				
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## **I. Introduction**

Breast cancer is a major public health problem in the United States accounting for nearly 30% of all cancers and 18% of all cancer deaths occurring in women (1). It affects one in nine white women, one in eleven black women and one in eighteen Hispanic and Chinese women in their lifetime. Based on current mortality rates in California, one in thirty black women, one in thirty-six white women and one in seventy Hispanic women, and one in eighty Chinese women will die of breast cancer.

Although about one quarter of cancer patients in the United States use alternative therapies (2,3), ethnic differences in the use and consequences of these therapies have not been examined. Our long range goal is to assess outcomes including cost, quality of life, recurrence and survival among breast cancer patients in four ethnic groups in San Francisco, California using conventional and alternative therapies.

The specific aims of this study are:

1. To determine the types of alternative and conventional therapies used by women in four different ethnic groups in San Francisco who were diagnosed with breast cancer between 1990 and 1992. The ethnic groups to be studied are Hispanics, whites, blacks, and Chinese--Americans.
2. To determine the prevalence of use of conventional and alternatives cancer therapies alone in combinations.
3. To assess the frequency and length of use of various medical care alternatives before and after cancer diagnosis confirmation.
4. To determine the influences, if any, of ethnicity, nativity (foreign vs. US born), length in the US, acculturation, family income, education, religion, social support, health insurance status, first degree family history of breast cancer, age at diagnosis, stage at diagnosis, node involvement, and estrogen receptor status on the use of different therapies.

We propose to conduct telephone interviews on approximately 400 breast cancer patients and assess their treatment choices and factors influencing the choice.

## **II. Task Completed in the Past Year**

1. A part-time research coordinator was hired in October 1994 who also speaks Chinese and serves as a Chinese interviewer. Another Spanish bilingual survey worker was hired in June 1995.
2. Approximately 600 abstract forms with medical and surgical information on women diagnosed with in situ and invasive breast cancer in San Francisco city and county between January 1990 to December 1992 were requested from the California Tumor Registry which was operated by the Northern California Cancer Center.

### 3. Development of the Survey Instrument

- (a) The questionnaire of the study was developed and translated into Chinese and Spanish in January 1995. (See Appendix I)
- (b) A physician letter, a deceased patient physician letter, a case letter and consent form were finalized in January 1995. (See Appendix II)
- (c) Pilot tested, revised and finalized the questionnaire in February 1995.
- (d) Back translating the translated questionnaire into English was completed in March 1995.
- (e) An interviewer's training manual has been prepared to explain the background and the purpose of the study, including question by question instructions of the survey questionnaire. (See Appendix III)

### 4. Telephone Survey and Data Processing

The telephone interviews began in March, between March 1 and August 15, 1995, a total of 369 physician letters were sent, and 264 case letters were mailed. 121 interviews have been completed. Of these, 35 were whites, 28 were blacks, 23 were Hispanics, and 35 were Chinese. All the completed surveys have been edited, and the collected data has been entered into the computer.

The following tables shows the preliminary data.

Table 1: Indicates case status as of 8/15/95

Chinese cases have the highest refusal. The reason for this needs further explanation. The other investigators from the Northern California Cancer Center have experienced similar high refusal in the past, there is suspicion and distrust in the Chinese community.

Table 2: Shows the type of treatment for breast cancer by four ethnic groups

It is evident that ethnic differences prevail in the use of various therapies for breast cancer. White cases used more dietary regimen and psychological methods than other ethnic groups. The other treatment was mainly Tamoxifen.

**Table 1**  
**Breast Cancer Therapy Study**  
**Case Status**

Date: 8/15/95

	White	Black	Hispanic	Chinese
Number of MD letters sent	76	81	92	130
Number MD refusals	1	4	0	1
Number deceased	5	11	6	10
Number subject letters sent	70	66	52	76
Number subjects on hold (NA/CB)	28	17	20	12
Number subjects being traced	2	14	5	6
Number deceased/no proxy	0	3	0	3
Number subjects refused	3	1	1	19
Number never had breast cancer	2	2	3	1
Number subjects completed interviews	35	28	23	35
Number questionnaire edited and coded	34	23	23	32
Number questionnaire key punched	34	23	23	27

**Table 2**  
**Types of Treatment for Breast Cancer**

	White %	Black %	Hispanic %	Chinese %
Surgery Yes	100	100	100	96
Chemotherapy Yes	29	30	43	31
Radiation Yes	57	35	57	42
Macrobiotics Yes	3	0	0	4
Megavitamins Yes	6	4	4	0
Other Diet Regimen Yes	26	4	13	12
Homeopathy Yes	3	4	0	0
Herbal Remedies Yes	9	9	4	12
Psychological Methods Yes	20	13	0	0
Physical Methods Yes	11	4	9	0
Immune Therapy Yes	0	0	0	0
Other Treatments Yes	23	22	48	19

## **Conclusions**

We will continue conducting telephone interviews for breast cancer patients in the next half year. Statistical data analysis will be performed in the last six months of the study. No changes of future work is recommended.

## References

1. Perkins C, Hoegh H, Wright WE, Young J. Cancer incidence and mortality of race/ethnicity in California 1988-1990. Cancer Surveillance Section, Department of Health Services, California 1993.
2. Lerner IJ, Kennedy BJ. The prevalence of questionable methods of cancer treatment in the United States. CA: A Cancer Journal for Clinicians 1992;42:181-191.
3. Cassileth BR, Brown H. Unorthodox cancer medicine. CA: A Cancer Journal for Clinicians 1988;38:176-186. We will continue conducting telephone interviews for breast cancer patients in the next half year. Statistical data analysis will be performed in the last six months of the study. No changes of future work is recommended.

## Appendix I

02/16/95

LD. \_\_\_\_\_

**Confidential Questionnaire**

**Department of Epidemiology and Biostatistics (Box 0560)  
University of California, San Francisco  
Choices of Breast Cancer Therapy Study  
(415) 476-0743**

Time Interview Started: \_\_\_\_\_  
Interviewer's Initials: \_\_\_\_\_  
Time Interview Ended: \_\_\_\_\_

Case's Diagnosis Date: \_\_\_\_\_  
Month      Date      Year

Today's Date: \_\_\_\_\_  
Month      Date      Year

☐ Check here if this is a proxy interview. What is your relationship to: \_\_\_\_\_?

Relationship: \_\_\_\_\_

How long have you known her? \_\_\_\_\_  
years      months

☐ Check here if case is deceased.

Hello, my name is \_\_\_\_\_ from the University of California, San Francisco. I am going to ask you a series of questions for the Choices of Breast Cancer Therapy study we are conducting. All information you give me is confidential and will be used only in statistical summaries. Please feel free to ask me for clarification if there is any question you do not understand.

Do you have any questions before we begin?

Quality of the interview:      Good \_\_\_\_\_      Fair \_\_\_\_\_      Poor \_\_\_\_\_

Questionnaire Edited By: \_\_\_\_\_ on \_\_\_\_\_  
initials      date

Study I.D.: \_\_\_\_\_

Date of Interview: \_\_\_\_\_

Name of Interviewer: \_\_\_\_\_

在我们开始这个访问之前，我需要确定一下您是不是我们访问的对象。  
Before we start the interview, I need to confirm your eligibility for our study.

- 請問有沒有醫生告訴過您，您有乳癌呢？  
1. Have you ever been diagnosed with breast cancer?

Yes

1

No

我們只訪問那些曾經患過乳癌的婦女，

2 [STOP!]

Right now we are interviewing only women who have had breast cancer.

But thank you very much for your willingness to help.

所以這次不能訪問您，但我非常謝謝您的合作。

Don't know

9 [SKIP TO Q3]

- 您的乳癌是甚麼時候診斷出來的呢？  
2. When were you first diagnosed with breast cancer?

\_\_\_\_ / \_\_\_\_  
month year

現在我想請問一些關於您自己的問題。  
Now I'd like to ask you some questions about yourself.

- 您家里最常講的是哪一種語言呢？  
3. What language is most often spoken in your home?

Spanish

1

Chinese

2

English

3

Both Spanish/English equally

4

Both Chinese/English equally

5

Other \_\_\_\_\_

6

Don't know

9

- 您認為您現在的健康情況如何呢？ 是不是：  
4. How would you rate your health nowadays? Would you say it is:  
(READ ALL CATEGORIES)

Excellent

非常好

1

Good

好

2

Fair

普普通通

3

Poor

很差

4

Don't know

9

5. 在医生还没有告诉您您有乳癌之前，您的健康情况如何呢？是不是：  
How would you rate your health during your adulthood before the breast cancer diagnosis? Would you say it was:

( READ ALL CATEGORIES )

Excellent	非常好	1
Good	好	2
Fair	普通/普通	3
Poor	很差	4
Don't know		9

6. 您的乳癌是怎样被发现的呢？是不是：  
How was your breast cancer first discovered?  
Was it:

( READ ALL CATEGORIES )

By yourself	由您自己发现	1	[SKIP TO Q7b]
By clinical exam	由乳部检查发现	2	
By mammogram	由乳部X光检查发现	3	
Other (specify) _____		4	
Don't know		9	

- 7a. 在还没有知道您有乳癌以前，您有没有注意到身体上可能有些不对呢？  
Before you were first diagnosed with breast cancer, did you notice that something might be wrong?

Yes	1	
No	2	[SKIP TO Q8]
Don't know	9	

- 7b. 您注意到些甚麼呢？  
What was it you noticed? [RECORD VERBATIM]

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- 7c. 您注意到身体上有些不对的时候是在乳癌的診斷被確定以前的多久呢？  
How long before the breast cancer diagnosis was confirmed did you notice that something was wrong?

(days)

(months)

## TREATMENT FOR BREAST CANCER

我現在要問的問題是關於一些您曾經用過來幫助控制或者醫治乳癌的治療方法。  
I'm going to ask you some questions about treatments and therapies you may have used to help you deal with breast cancer.

8. 在被診斷出有乳癌之後，您有沒有做過( )呢？  
As a result of the diagnosis of breast cancer, did you have (treatment)?

(READ ALL THE CATEGORIES)

		Yes	No	DK
a. Surgery	手術	1	2	9
b. Chemotherapy	化學療法	1	2	9
c. Radiation therapy	放射性治療法	1	2	9

- 在被診斷出有乳癌之後，您有沒有嘗試過( )呢？  
As a result of the diagnosis of breast cancer, have you tried (treatment)?

(READ ALL THE CATEGORIES)

		Yes	No	DK
d. Macrobiotic diet	一種服食大量穀類的飲食療法	1	2	9
e. Megavitamin therapy	服食大量維生素的治療法	1	2	9
f. Other dietary therapy	其他飲食療法			
	(Specify _____)	1	2	9
g. Homeopathy	顺势治療法	1	2	9
h. Herbal remedies	中藥藥	1	2	9
i. Psychological methods	心理療法			
	(e.g. meditation, imagery) (如默想、想像精力)	1	2	9
j. Faith/spiritual healing	信心/心靈療法	1	2	9
k. Physical methods	物理療法 (如按摩、放鬆、指壓、針灸)			
	(e.g. massage, relaxation, acupressure/ acupuncture)	1	2	9
l. Immune therapy	免疫療法			
	(e.g. Livingston Therapy, IAT)	1	2	9

9. 您還有沒有嘗試過任何其他的乳癌治療方法呢？  
Were there any other treatments or therapies  
you tried as a result of your breast cancer diagnosis?

(If yes, please specify \_\_\_\_\_)

现在我想问些问题给您用的每个比发表的问题。我们使一个开始。  
 Now I'm going to ask some questions about each of these treatments you have had or used  
 after the breast cancer diagnosis.  
 Let's start with the first one.

	SURGERY	RECONSTRUCTIVE SURGERY																																				
10a. Did you have ... 您有没有做过...	<p>您做过吗？</p> <table border="0"> <tr> <td>Yes</td> <td>No</td> <td>How Many?</td> </tr> <tr> <td>1</td> <td>2</td> <td></td> </tr> </table> <p>a. Biopsy?            活检</p> <table border="0"> <tr> <td>Yes</td> <td>No</td> <td>How Many?</td> </tr> <tr> <td>1</td> <td>2</td> <td></td> </tr> </table> <p>b. Lumpectomy?            局部切除术</p> <table border="0"> <tr> <td>Yes</td> <td>No</td> <td>How Many?</td> </tr> <tr> <td>1</td> <td>2</td> <td></td> </tr> </table> <p>c. Modified radical mastectomy?            局部乳房切除术</p> <table border="0"> <tr> <td>Yes</td> <td>No</td> <td>How Many?</td> </tr> <tr> <td>1</td> <td>2</td> <td></td> </tr> </table> <p>d. Radical mastectomy?            全部乳房切除术</p> <table border="0"> <tr> <td>Yes</td> <td>No</td> <td>How Many?</td> </tr> <tr> <td>1</td> <td>2</td> <td></td> </tr> </table> <p>ASK THE REMAINING QUESTIONS BASE ON THE MOST SEVERE SURGERY THAT THE RESPONDENT HAD.</p>	Yes	No	How Many?	1	2		Yes	No	How Many?	1	2		Yes	No	How Many?	1	2		Yes	No	How Many?	1	2		Yes	No	How Many?	1	2		<p>您有没有做过乳房整形手术呢？</p> <p>Did you have reconstructive surgery?</p> <table border="0"> <tr> <td>Yes</td> <td>No</td> <td>How Many?</td> </tr> <tr> <td>1</td> <td>2</td> <td></td> </tr> </table> <p>IF "NO", GO TO NEXT TREATMENT.            是否基麻时候呢？            When?</p> <p>month      day      year</p>	Yes	No	How Many?	1	2	
Yes	No	How Many?																																				
1	2																																					
Yes	No	How Many?																																				
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1	2																																					

	SURGERY	RECONSTRUCTIVE SURGERY	CHEMOTHERAPY	RADIATION
10b. Over how long a time period did you have this/these (treatment)? 你採用這(治療法)有多久呢?			_____ days _____ months _____ years	_____ days _____ months _____ years
19a. Do you think that this (treatment) has helped you? 您認為這(治療法)對您有幫助嗎?	Yes _____ No _____ Dk _____ 1 2 9 IF "NO" OR "DK", SKIP TO Q20a.	Yes _____ No _____ Dk _____ 1 2 9 IF "NO" OR "DK", SKIP TO Q20a.	Yes _____ No _____ Dk _____ 1 2 9 IF "NO" OR "DK", SKIP TO Q20a.	Yes _____ No _____ Dk _____ 1 2 9 IF "NO" OR "DK", SKIP TO Q20a.
19b. IF RESPONDED HELPFUL: In what way do you feel the (treatment) has helped you? [RECORD VERBATIM] 你覺得這(治療法)在哪些方面對你有幫助呢?	_____ _____ _____ _____	_____ _____ _____ _____	_____ _____ _____ _____	_____ _____ _____ _____
20a. Are there any ways in which this (treatment) has harmed you? 你認為這(治療法)對你有任何的傷害嗎?	Yes _____ No _____ Dk _____ 1 2 9 IF "NO" OR "DK", SKIP TO Q21.	Yes _____ No _____ Dk _____ 1 2 9 IF "NO" OR "DK", SKIP TO Q21.	Yes _____ No _____ Dk _____ 1 2 9 IF "NO" OR "DK", SKIP TO Q21.	Yes _____ No _____ Dk _____ 1 2 9 IF "NO" OR "DK", SKIP TO Q21.

	SURGERY	RECONSTRUCTIVE SURGERY	CHEMOTHERAPY	RADIATION
20b. IF RESPONDED HARMFUL: 您覺得這(治療法)或哪些 In what ways do you feel this (treatment) has harmed you? [RECORD VERBATIM] 方劑對您有傷害嗎?	_____ _____ _____ _____	_____ _____ _____ _____	_____ _____ _____ _____	_____ _____ _____ _____
21. 依您這次的經驗, 如果 一個患乳腺癌的人來問您 Given this experience, if someone with breast cancer asked you, would you recommend this treatment?	Yes _____ No _____ Dk _____ 1        2        9	Yes _____ No _____ Dk _____ 1        2        9	Yes _____ No _____ Dk _____ 1        2        9	Yes _____ No _____ Dk _____ 1        2        9
22. 您(將)來接受這(治療法) How far, in round trip distance and/or total time did you have to travel to receive (treatment) each time (FOR CHEMOTHERAPY AND RADIATION ONLY) ?	distance (miles) _____ time (minutes) _____ No travel involved 0 Don't know 999	distance (miles) _____ time (minutes) _____ No travel involved 0 Don't know 999	distance (miles) _____ time (minutes) _____ No travel involved 0 Don't know 999	distance (miles) _____ time (minutes) _____ No travel involved 0 Don't know 999

	SURGERY	RECONSTRUCTIVE SURGERY	CHEMOTHERAPY	RADIATION
23. Was all or any part of the cost for the (treatment) covered by insurance? 你的保險是不是包括了這(治療)的全部或者是一部份的費用呢?	Yes, all (GO TO RECONSTRUCTIVE SURGERY) 1 Yes, some 2 No 3 Don't know 9	Yes, all (GO TO NEXT TREATMENT) 1 Yes, some 2 No 3 Don't know 9	Yes, all (GO TO NEXT TREATMENT) 1 Yes, some 2 No 3 Don't know 9	Yes, all (GO TO NEXT TREATMENT) 1 Yes, some 2 No 3 Don't know 9
24b. What was the total amount you were responsible for paying for this (treatment) altogether? 這(治療)您一共要自己付多少錢呢?	\$ _____ Don't know 9	\$ _____ Don't know 9	\$ _____ Don't know 9	\$ _____ Don't know 9



	TREATMENT:	TREATMENT:	TREATMENT:	TREATMENT:
13. Where did you first learn about the (treatment). . . from a family member, friend, media (TV, radio, newspaper, magazine), medical doctor, nurse, other healers, or other sources? 你最初是從哪兒知道這種(治療)的呢?	Allow multiple answers Family 1 Friend 2 Media 3 Health professional (specify) 4 Other (specify) 5 Don't know 9	Allow multiple answers Family 1 Friend 2 Media 3 Health professional (specify) 4 Other (specify) 5 Don't know 9	Allow multiple answers Family 1 Friend 2 Media 3 Health professional (specify) 4 Other (specify) 5 Don't know 9	Allow multiple answers Family 1 Friend 2 Media 3 Health professional (specify) 4 Other (specify) 5 Don't know 9
14. Did you talk with your medical doctor about using the (treatment)? 您有沒有跟您的主治醫生談過用這種(治療)呢?	Yes 1 No 2 Don't know 9 (SKIP to Q 16a)	Yes 1 No 2 Don't know 9 (SKIP to Q 16a)	Yes 1 No 2 Don't know 9 (SKIP to Q 16a)	Yes 1 No 2 Don't know 9 (SKIP to Q 16a)

	TREATMENT:	TREATMENT:	TREATMENT:	TREATMENT:
15. 你的醫生有甚麼反應呢? What was your medical doctor's response? 他是同意、反對、或沒有 反應? 你曾試過(或要求)呢? Did s/he recommend, agree, or object to your trying the (treatment)?	Recommended 1 Agreed 2 Objected 3 Don't know 9	Recommended 1 Agreed 2 Objected 3 Don't know 9	Recommended 1 Agreed 2 Objected 3 Don't know 9	Recommended 1 Agreed 2 Objected 3 Don't know 9
16a. How many times per day/week/month/year did you use the (treatment)? 你每天/星期/月/年 用這(或藥水)多少次呢?	_____ /day; _____ /week; _____ /month; _____ /year Don't know 99	_____ /day; _____ /week; _____ /month; _____ /year Don't know 99	_____ /day; _____ /week; _____ /month; _____ /year Don't know 99	_____ /day; _____ /week; _____ /month; _____ /year Don't know 99

	TREATMENT:	TREATMENT:	TREATMENT:	TREATMENT:
16b. For how long a time period did you use the (treatment) altogether? 您共用了這(治療法)多久呢?	_____ months      years Don't know      99	_____ months      years Don't know      99	_____ months      years Don't know      99	_____ months      years Don't know      99
17. Are you still using the (treatment)? 您是不是仍然在用這(治療法)呢?	Yes      1 (SKIP to Q19) No      2 Don't know      9	Yes      1 (SKIP to Q19) No      2 Don't know      9	Yes      1 (SKIP to Q19) No      2 Don't know      9	Yes      1 (SKIP to Q19) No      2 Don't know      9

	TREATMENT:	TREATMENT:	TREATMENT:	TREATMENT:
18. Why did you stop? 你甚麼時候停了?	One time treatment 1 Too expensive 2 No change in condition 3 Condition improved 4 Condition worsened 5 Uncomfortable/painful side effects of treatment 6 Advice of MD 7 Other (specify) _____ _____ 8 Don't know 99	One time treatment 1 Too expensive 2 No change in condition 3 Condition improved 4 Condition worsened 5 Uncomfortable/painful side effects of treatment 6 Advice of MD 7 Other (specify) _____ _____ 8 Don't know 99	One time treatment 1 Too expensive 2 No change in condition 3 Condition improved 4 Condition worsened 5 Uncomfortable/painful side effects of treatment 6 Advice of MD 7 Other (specify) _____ _____ 8 Don't know 99	One time treatment 1 Too expensive 2 No change in condition 3 Condition improved 4 Condition worsened 5 Uncomfortable/painful side effects of treatment 6 Advice of MD 7 Other (specify) _____ _____ 8 Don't know 99

	TREATMENT:	TREATMENT:	TREATMENT:	TREATMENT:
19a. Do you think that this (treatment) has helped you? 你認為這( )對你有幫助嗎?	Yes No Dk 1 2 9 IF "NO" OR "DK", SKIP TO Q20a.	Yes No Dk 1 2 9 IF "NO" OR "DK", SKIP TO Q20a.	Yes No Dk 1 2 9 IF "NO" OR "DK", SKIP TO Q20a.	Yes No Dk 1 2 9 IF "NO" OR "DK", SKIP TO Q20a.
19b. IF RESPONDED HELPFUL: 你覺得這( )有幫助嗎? In what way do you feel the (treatment) has helped you? [RECORD VERBATIM]				
20a. Are there any ways in which this (treatment) has harmed you? 你認為這( )對你有什麼傷害嗎?	Yes No Dk 1 2 9 IF "NO" OR "DK", SKIP TO Q21.	Yes No Dk 1 2 9 IF "NO" OR "DK", SKIP TO Q21.	Yes No Dk 1 2 9 IF "NO" OR "DK", SKIP TO Q21.	Yes No Dk 1 2 9 IF "NO" OR "DK", SKIP TO Q21.
20b. IF RESPONDED HARMFUL: 你覺得這( )有傷害嗎? In what ways do you feel this (treatment) has harmed you? [RECORD VERBATIM]				

	TREATMENT:	TREATMENT:	TREATMENT:	TREATMENT:
21. 你这次的经验, 如果一个人 Given your experience, if someone with breast cancer asked you, would you recommend this treatment?	Yes No Dk 1 2 9	Yes No Dk 1 2 9	Yes No Dk 1 2 9	Yes No Dk 1 2 9
22. How far in round trip distance and/or total time did you have to travel to receive the (treatment) each time? 你每次去医院 ( ) 来回 要花多少时间和/或者来回的 路程有多远呢?	distance (miles) time (minutes) No travel involved 0 Don't know 999	distance (miles) time (minutes) No travel involved 0 Don't know 999	distance (miles) time (minutes) No travel involved 0 Don't know 999	distance (miles) time (minutes) No travel involved 0 Don't know 999
23. Was all or any part of the cost for the (treatment) covered by insurance? 你的保险是不是包括了 这 ( ) 部分的费用或者 是一部分的费用呢?	Yes, all 1 Yes, some 2 No 3 Don't know 9 (SKIP to Q25)	Yes, all 1 Yes, some 2 No 3 Don't know 9 (SKIP to Q25)	Yes, all 1 Yes, some 2 No 3 Don't know 9 (SKIP to Q25)	Yes, all 1 Yes, some 2 No 3 Don't know 9 (SKIP to Q25)

	TREATMENT:	TREATMENT:	TREATMENT:	TREATMENT:
	_____	_____	_____	_____
24a. What was the average amount you were responsible for paying each visit? 你每次访问( )平均要付多少钱呢?	\$ _____ Don't know 9	\$ _____ Don't know 9	\$ _____ Don't know 9	\$ _____ Don't know 9
24b. What was the total amount you were responsible for paying for this treatment altogether? 这( )你一共要付自己付多少钱呢?	\$ _____ Don't know 9	\$ _____ Don't know 9	\$ _____ Don't know 9	\$ _____ Don't know 9
25. Did you use or have this (treatment) 2 years before the breast cancer diagnosis? 你在被诊断出患有乳腺癌之前的两年内有没有用过( )呢?	Yes No Dk 1 2 9	Yes No Dk 1 2 9	Yes No Dk 1 2 9	Yes No Dk 1 2 9

26. 下面我會讀一些病徵給你聽。請你告訴我在我被診斷出有乳癌的兩年前，你曾經有這些病徵  
Now I'm going to read a list of conditions and symptoms. Please tell me if you had any of these conditions and symptoms in the 2 years before the breast cancer 出現過嗎?  
diagnosis? Please answer yes or no.

(READ ALL THE CATEGORIES)

	Yes	No	DK
乳癌以外的腫瘤或者癌症			
a. Tumor or cancer (other than breast cancer)	1	2	9
消化方面的毛病			
b. Digestive problems	1	2	9
尿道/膀胱的毛病			
c. Urinary/bladder problems	1	2	9
婦科/月經的毛病			
d. Gynecological/menstrual problems	1	2	9
皮膚的毛病			
e. Skin problems	1	2	9
太胖			
f. Obesity	1	2	9
憂鬱			
g. Depression	1	2	9
失眠			
h. Insomnia	1	2	9
感染到愛滋病的病毒			
i. Human Immunodeficiency Virus (HIV)	1	2	9
關節炎			
j. Arthritis	1	2	9
腰痛或背痛			
k. Back problems	1	2	9
頭痛			
l. Headaches	1	2	9
其他			
m. Other ( If yes, specify _____ )	1	2	9

現在我想問些關於你的家庭歷史的問題

Now I'd like to ask you some questions about your family history.

27. 你母親有沒有曾經患過乳癌呢?  
Did your mother ever have breast cancer?

Yes

1

No

2

Don't know

9

28. 你有多少位姐妹呢? 請包括同父異母或者同母異父的姐妹?  
How many natural sisters, including half sisters, do you have? \_\_\_\_\_

[IF NONE, SKIP TO QUESTION 30]

29. 她/她们當中有没有任何人患過乳癌呢?  
Did any of them/she ever have breast cancer?

Yes [Specify how many \_\_\_\_\_]

1

No

2

Don't know

9

30. 您有多少個女兒呢?  
How many daughters do you have? \_\_\_\_\_

[IF NONE, SKIP TO QUESTION 32]

31. 她/她们當中有没有任何人患過乳癌呢?  
Did any of them/she ever have breast cancer?

Yes [Specify how many \_\_\_\_\_]

1

No

2

Don't know

9

32. 您的祖母或外祖母有没有曾经患過乳癌呢?  
Did either of your grandmothers ever have breast cancer?

Yes [Specify paternal/maternal/both \_\_\_\_\_]

1

No

2

Don't know

9

33. 您的好朋友當中有没有得過乳癌的呢?  
Did any of your close friends ever have breast cancer?

Yes

1

No

2

Don't know

9

[IF YES FOR ANY RELATIVES AND/OR FRIENDS, ASK Q34;  
OTHERWISE SKIP TO Q35.]

34. 因為您的親人或者是好朋友曾經患過乳癌 她們有没有影响到您對  
Did the fact that your relative(s) and/or close friend(s) had breast cancer influence  
your choices of breast cancer treatments?  
選擇乳癌治療方法的決定呢?

Yes

1

No

2

Don't know

9

35. 在患乳癌之前，您有沒有每個月最少參加一次下面的團體呢？  
Before the breast cancer diagnosis, did you participate in any of the following kinds of groups at least once a month?

( READ ALL CATEGORIES )

	YES	NO	DK
一個宗教團體 A religious group?	1	2	9
一個非宗教性質的社交或者娛樂團體 A non-religious social or recreational group?	1	2	9
一個工會、商業團體、專業人士協會 A labor union, commercial group, or professional association?	1	2	9
一個跟小孩有關的團體，例如家長會、男童軍 A group concerned with children, such as PTA or Boy Scouts?	1	2	9
一個改善社區、慈善、或者服務性的團體？ A group concerned with community betterment, charity, or service?	1	2	9
任何其他團體 Any other group? _____	1	2	9

36. 在您患乳癌之前，您對您個人的生活有多滿意呢？是非常滿意、一般滿意、或者普通、一般不滿意、或者是非常不滿意呢？  
Before you were diagnosed with breast cancer, how satisfied were you with your personal life? Would you say very satisfied, generally satisfied, somewhat satisfied, generally dissatisfied, or very dissatisfied? 大致上滿意、普普通通、大致上都不滿意、或者是非常不滿意呢？

Very satisfied	1
Generally satisfied	2
Somewhat satisfied	3
Generally dissatisfied	4
Very dissatisfied	5
Don't know	9

37. 就您在患乳癌之前您對個人生活的滿意程度來講，請您告訴我您對下面的情形您是覺得很差、普普通通、好、很好或是非常好。  
In terms of your satisfaction with your personal life before the breast cancer diagnosis, please rate the following as poor, fair, good, very good, or excellent:

( READ ALL CATEGORIES )

	poor	fair	good	very good	excellent
您跟家人或者朋友的親密程度 The amount of togetherness and cohesion you had with either family or friends	1	2	3	4	5
您跟家人或者朋友互相支持和了解的程度 The support and understanding you gave each other	1	2	3	4	5
您跟家人或者朋友之間有商有量的程度 The amount you talked things over	1	2	3	4	5

38. 在您患乳癌之前，您通常對您平常做的事情是否常常都喜歡做，通常都喜歡做。  
Before this breast cancer diagnosis, how much of the time did you enjoy the things you did? Would you say all of the time, usually, sometimes, a little of the time, or never? 有時候喜歡做，很少喜歡做，或者是從來不喜歡做呢？

All of the time	1
Usually	2
Sometimes	3
A little of the time	4
Never	5
Don't know	9

39. 自從您發現您有乳癌之後，您有沒有開始，停止，繼續做或者是繼續不做  
Since you found out that you had breast cancer, have you started, stopped, continued to do, or continued not to do each of these things: 下面這些事情呢？

( READ ALL CATEGORIES )	<u>started</u>	<u>stopped</u>	<u>continued to do</u>	<u>continued not to do</u>
做運動 Exercising	1	2	3	4
吸菸 Smoking	1	2	3	4
喝酒 Drinking alcohol	1	2	3	4
接受任何的輔導 Counseling of any kind	1	2	3	4
參加一個互助團體 Attending a support group	1	2	3	4

Now I'd like to ask you a few questions about your menstrual history and background. 現在我想問您一些關於月經的問題。

40. 您第一次來月經的時候年紀有多大呢？  
How old were you when you had your first menstrual period? \_\_\_\_\_  
(years)

41. 您到了「更年期」沒有呢？  
Have you reached menopause, also known as "the change of life"?

Yes	1	
No	2	[SKIP TO Q43]
Don't know	9	

42. 您最後一次來月經的時候年紀多大呢？  
How old were you when you had your last menstrual period? \_\_\_\_\_  
(years)

43. 您懷孕過多少次呢？請包括所有的懷孕、順產、胎死腹中、小產、宮外/輸卵管受孕和墮胎。  
How many times have you been pregnant? Please include all pregnancies, live births, still births, miscarriages, tubal or ectopic pregnancies, and abortions.

44. 您是在哪一個國家出生的呢？  
In what country were you born?

U.S.A.

1 [SKIP TO Q46]

Other \_\_\_\_\_

2

Don't know

9

45. 您在美国住了多少年呢？  
How many years have you lived in the U.S.?

\_\_\_\_\_  
(years)

46. 您在三藩市住了多久呢？  
How long have you lived in San Francisco?

\_\_\_\_\_  
(years)

47. 当您知道您有乳癌的那一段时间...  
Around the time when the breast cancer was diagnosed...

- a. 您是不是一个人住呢？  
Were you living alone?

Yes

1

No

2

Don't know

9

- b. 您当时的婚姻状况是如何呢？  
What was your marital status then?

Married or living with someone

1

Previously married, now single

2

Never married

3

Don't Know

9

47c. 你當時的宗教信仰是甚麼呢？  
What was your religion at the time of your breast cancer diagnosis?

- |                   |    |
|-------------------|----|
| Protestant        | 1  |
| Catholic          | 2  |
| Jewish            | 3  |
| Islam/Muslim      | 4  |
| Buddhist          | 5  |
| Ancestor worship  | 6  |
| Other _____       | 7  |
| Combination _____ | 8  |
| No Preference     | 9  |
| None              | 10 |

d. 在您知道有乳癌的那段時期，你有哪一種民藥保險呢？例如...  
Around the time when the breast cancer was diagnosed, what kind of health care coverage or insurance did you have, if any, such as Kaiser, Health Net, Take Care, Blue Cross, Blue Shield, MediCal, or Medicare?

- |   |   |
|---|---|
| Government (MediCal, Medicare, Veterans Administration) | 1 |
| Private insurance or HMO _____                          | 2 |
| None  | 3 |
| Don't know  | 9 |

48. 不包括英文班跟職業訓練班，你最高唸到幾年級呢？  
What was the highest grade of school you have completed, not including English language classes and job training classes?

- |                      |   |
|----------------------|---|
| None                 | 1 |
| Elementary           | 2 |
| Junior High          | 3 |
| High School          | 4 |
| Some Undergraduate   | 5 |
| Undergraduate Degree | 6 |
| Graduate School      | 7 |
| Don't know           | 9 |

最後,我想問問您全家人的收入。我們很明白收入可能是很難估計的。但是  
 Finally, I have a question about your household income. We understand that it may be difficult to estimate income. However, this information will help us to understand more about the factors influencing treatment choices in our community. This information as all other data will be strictly confidential. 這些資料可以幫助我們了解多一點我們社區所需要的健康補助,這些資料是完全保密的。

49. During the last year (199\_\_), how many people depended on your total household income?  
 在去年(199\_\_)年,有多少人依靠這份收入來生活呢?\_\_\_\_\_

50. I would like to read you a list of income categories. Please estimate the approximate total pre-tax income of your household for the last year, 199\_\_? Please include money received from job wages, social security income, retirement benefits, unemployment benefits, welfare programs, etc. Would you say:  
 (READ ALL CATEGORIES) 現在我會唸一些收入項目給您聽。

Less than \$10,000	請您估計一下,在去年(199__)年,您全家一年在沒有扣稅以前一共的收入大概有多少。請您包括	1
\$10,001-\$20,000	薪金、社會保障收入、退休福利、失業福利和政府補助等等。	2
\$20,001-\$40,000	是不是...	3
\$40,001-\$60,000		4
\$60,001 or more		5
Refused		8
Don't know		9

51. 如果您搬了家而我們需要跟您聯絡,您有沒有兩位親戚或者好朋友  
 Are there two people, close friends or relatives, that we could contact in case you move and we need to contact you? What are their names and telephone numbers? 可以讓我們跟他們聯絡呢?請您告訴我他們的姓名和電話可以嗎?

Name

Phone number

1) \_\_\_\_\_

2) \_\_\_\_\_

52. 我已經完成訪問了。請問您有沒有任何意見或者問題呢?  
 Those are all the questions I have for you. Do you have any comments or questions?

\_\_\_\_\_

\_\_\_\_\_

53. [DO NOT READ] Did subject request results?

Yes  
 No

1  
 2

THANK YOU VERY MUCH FOR YOUR PARTICIPATION.

06/01/95

I. D. \_\_\_\_\_

**Cuestionario Confidencial**

**Departamento de Epidemiología y Bioestadísticas (Box 0560)**  
**Universidad de California, San Francisco**  
**Estudio sobre Alternativas de Terapia para el Cáncer en el Seno**  
**(415)476-0743**

Tiempo en que comenzó la entrevista: \_\_\_\_\_ Fecha en que se diagnosticó el caso: \_\_\_\_\_

Iniciales del entrevistador: \_\_\_\_\_

\_\_\_\_\_

Mes      Día      Año

Tiempo en que terminó la entrevista: \_\_\_\_\_

Fecha del día de hoy: \_\_\_\_\_

\_\_\_\_\_

Mes      Día      Año

Marque aquí si la entrevista es con un apoderado. ¿Cuál es la relación con: \_\_\_\_\_?

Relación: \_\_\_\_\_

¿Por cuánto tiempo la ha conocido? \_\_\_\_\_

Años      Meses

Marque aquí si la persona ha muerto.

Hola, mi nombre es \_\_\_\_\_ de la Universidad de California, en San Francisco. Le voy a hacer una serie de preguntas para un estudio que estamos haciendo sobre las alternativas de terapia para el cáncer en el seno. Toda la información que usted me da es confidencial y será usada únicamente en resúmenes estadísticos. Por favor sientase con toda libertad de pedirme que le aclare si hay alguna pregunta que no entiende.

¿Tiene alguna pregunta antes de que empecemos?

Calidad de la entrevista: Buena \_\_\_\_\_ Regular \_\_\_\_\_ Mala \_\_\_\_\_

Cuestionario editado por: \_\_\_\_\_ el \_\_\_\_\_

Iniciales

Fecha

Estudio #: \_\_\_\_\_

Fecha de la entrevista: \_\_\_\_\_

Nombre del Entrevistador: \_\_\_\_\_

**Antes de comenzar la entrevista, necesito confirmar si Ud. califica para nuestro estudio.**

1. ¿Alguna vez le han diagnosticado cáncer en el seno?

Sí  
No

1  
2 (¡PARE!)

Ahora sólo estamos entrevistando a mujeres que hayan tenido cáncer en el seno. Pero muchas gracias por estar dispuesta a ayudar.

No sabe

9 PASE AL 3

2. ¿Cuándo le diagnosticaron por primera vez  
cáncer en el seno

\_\_\_\_/\_\_\_\_  
mes año

**Ahora me gustaría hacerle unas preguntas acerca de Ud.**

3. ¿Qué idioma se habla más a menudo en la casa?

Español  
Dialecto Chino  
Inglés  
Ambos Español/Inglés por igual  
Ambos Dialecto Chino/Inglés por igual  
Otro \_\_\_\_\_  
No sabe

1  
2  
3  
4  
5  
6  
9

4. ¿Cómo catalogaría su salud en este momento? Diría que es:  
(LEA TODAS LAS CATEGORIAS)

Excelente  
Buena  
Regular  
Mala  
No sabe

1  
2  
3  
4  
9

5. ¿Cómo catalogaría su salud como adulta antes de que le diagnosticaran cáncer en el seno? Diría que era:  
(LEA TODAS LAS CATEGORIAS)

Excelente	1
Buena	2
Regular	3
Mala	4
No sabe	9

6. ¿Cómo le descubrieron el cáncer en el seno?  
Fué:

(LEA TODAS LAS CATEGORIAS)

Ud. misma	1 (PASE AL 7b)
Un examen médico	2
Un mamograma	3
Otro (especifique) _____	4
No sabe	9

- 7a. ¿Antes de que le diagnosticaran cáncer en el seno, notó que algo podría andar mal?

Sí	1
No	2 (PASE AL 8)
No sabe	9

- 7b. ¿Qué fué lo que notó? (ESCRIBA PALABRA POR PALABRA)

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- 7c. ¿Cuánto tiempo antes de que el diagnóstico de cáncer en el seno fuera confirmado notó Ud. que algo podía andar mal?

\_\_\_\_\_  
(días)

\_\_\_\_\_  
(meses)

## TRATAMIENTO PARA CANCER EN EL SENO

Le voy a hacer algunas preguntas acerca de los tratamientos y terapias que Ud. puede haber usado para ayudar a controlar el cáncer en el seno.

8. Como resultado del diagnóstico del cáncer en el seno, ¿recibió (tratamiento)?

(LEA TODAS LAS CATEGORIAS)                      Sí    No    No sabe

a. Cirugía	1	2	9
b. Quimioterapia	1	2	9
c. Radiación	1	2	9

Como resultado del diagnóstico del cáncer en el seno, ha probado (tratamiento)?

(LEA TODAS LAS CATEGORIAS)                      Sí    No    No sabe

d. Dieta macrobiótica	1	2	9
e. Terapia de megavitaminas	1	2	9
f. Otra terapia dietética (Especifique _____ )	1	2	9
g. Homeopatía	1	2	9
h. Remedios de hierbas	1	2	9
i. Métodos psicológicos (ej., meditación, visualización)	1	2	9
j. Fé/Cura espiritual	1	2	9
k. Métodos físicos (ej., masajes, relajación, acupresión/ acupuntura)	1	2	9
l. Terapia de inmunización (ej., Terapia de Livingston, I A T)	1	2	9

9. ¿Ha habido cualquier otro tratamiento o terapia que haya probado como resultado del diagnóstico del cáncer en el seno?

1            2            9

(Si sí, por favor especifique \_\_\_\_\_ )

Ahora le voy a hacer algunas preguntas acerca de cada uno de los tratamientos que Ud. ha tenido o seguido después del diagnóstico del cáncer en el seno.  
Vamos a empezar con el primero.

	CIRUGIA	CIRUGIA RECONSTRUCTIVA
10a. ¿Le hicieron . . .	<p> <u>      </u> Sí <u>      </u> No <u>      </u> Cuántas? </p> <p> a. Biopsia ?            1            2            <u>      </u> </p> <p> b. Lumpectomía?      1            2            <u>      </u> </p> <p> c. Mastectomía Radical Modificada? </p> <p>                                  1            2            <u>      </u> </p> <p> d. Mastectomía Radical? </p> <p>                                  1            2            <u>      </u> </p> <p> <b>HAGA EL RESTO DE LAS PREGUNTAS BASADAS EN LA CIRUGIA MAS SEVERA QUE LA ENTREVISTADA HAYA TENIDO.</b> </p>	<p>¿Le hicieron cirugía reconstructiva?</p> <p> <u>      </u> Sí <u>      </u> No <u>      </u> ¿Cuántas? </p> <p>                                  1            2            <u>      </u> </p> <p> <b>SI "NO", PASE AL SIGUIENTE TRATAMIENTO.</b> </p> <p> ¿Cuándo?            <u>      </u>            <u>      </u>            <u>      </u> </p> <p>                                  mes            día            año </p>

	CIRUGIA	CIRUGIA RECONSTRUCTIVA	QUIMIOTERAPIA	RADIACION
10b. ¿Por cuánto tiempo siguió este/estos ( <i>tratamiento(s)</i> )?				
	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>	<div> <div>días</div> <div>meses</div> <div>años</div> </div>
19a. ¿Siente Ud. que este ( <i>tratamiento</i> ) la ha ayudado?	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>
19b. SI RESPONDIO QUE LA AYUDO:  ¿De qué manera siente Ud. que la ha ayudado el ( <i>tratamiento</i> )? [ESCRIBA PALABRA POR PALABRA]	<div>_____</div> <div>_____</div> <div>_____</div> <div>_____</div>	<div>_____</div> <div>_____</div> <div>_____</div> <div>_____</div>	<div>_____</div> <div>_____</div> <div>_____</div> <div>_____</div>	<div>_____</div> <div>_____</div> <div>_____</div> <div>_____</div>
20a. ¿La ha hecho daño de alguna manera este ( <i>tratamiento</i> )?	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>	<div> <div>Sí</div> <div>No</div> <div>No sabe</div> </div> <div> <div>1</div> <div>2</div> <div>9</div> </div>

	CIRUGIA	CIRUGIA RECONSTRUCTIVA	QUIMIOTERAPIA	RADIACION
20b. SI RESPONDIO QUE LE HIZO DAÑO:  ¿De qué manera siente Ud. que le hizo daño este (tratamiento)? [ESCRIBA PALABRA POR PALABRA]	_____	_____	_____	_____
21. Dada esta experiencia, ¿si alguien con cáncer en el seno le preguntara, recomendaría Ud. este tratamiento?	Sí _____ No _____ No sabe _____ 1      2      9	Sí _____ No _____ No sabe _____ 1      2      9	Sí _____ No _____ No sabe _____ 1      2      9	Sí _____ No _____ No sabe _____ 1      2      9
22. ¿Qué distancia ida y vuelta y/o cuánto tiempo tenía que viajar cada vez que recibía (tratamiento)? cada vez (SOLO PARA QUIMIOTERAPIA Y RADIACION)	distancia (millas) _____ tiempo (minutos) _____ No tenía que viajar 0 No sabe 999	distancia (millas) _____ tiempo (minutos) _____ No tenía que viajar 0 No sabe 999	distancia (millas) _____ tiempo (minutos) _____ No tenía que viajar 0 No sabe 999	distancia (millas) _____ tiempo (minutos) _____ No tenía que viajar 0 No sabe 999

	CIRUGIA	CIRUGIA RECONSTRUCTIVA	QUIMIOTERAPIA	RADIACION
23. ¿Fue todo o parte del costo del (tratamiento) pagado por una compañía de seguros?	<p>Sí, todo 1</p> <p>(PASE A CIRUGIA RECONSTRUCTIVA)</p> <p>Sí, algo 2</p> <p>No 3</p> <p>No sabe 9</p>	<p>Sí, todo 1</p> <p>(PASE AL SIGUIENTE TRATAMIENTO)</p> <p>Sí, algo 2</p> <p>No 3</p> <p>No sabe 9</p>	<p>Sí, todo 1</p> <p>(PASE AL SIGUIENTE TRATAMIENTO)</p> <p>Sí, algo 2</p> <p>No 3</p> <p>No sabe 9</p>	<p>Sí, todo 1</p> <p>(PASE AL SIGUIENTE TRATAMIENTO)</p> <p>Sí, algo 2</p> <p>No 3</p> <p>No sabe 9</p>
24b. ¿Cuál fué la cantidad total de la que Ud fué responsable de pagar por este (tratamiento)?	<p>\$ _____</p> <p>No sabe 9</p>	<p>\$ _____</p> <p>No sabe 9</p>	<p>\$ _____</p> <p>No sabe 9</p>	<p>\$ _____</p> <p>No sabe 9</p>

	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:
11. ¿Por favor describa en que consistía el ( <i>tratamiento</i> )? [ESCRIBA PALABRA POR PALABRA]	_____  _____  _____  _____  _____  _____  _____	_____  _____  _____  _____  _____  _____  _____	_____  _____  _____  _____  _____  _____  _____	_____  _____  _____  _____  _____  _____  _____
12. ¿Quién le dió tratamiento?	Yo misma Un doctor Un Oncólogo Otro (Especifique _____)  _____  _____  _____) )  No sabe	Yo misma Un doctor Un Oncólogo Otro (Especifique _____)  _____  _____  _____) )  No sabe	Yo misma Un doctor Un Oncólogo Otro (Especifique _____)  _____  _____  _____) )  No sabe	Yo misma Un doctor Un Oncólogo Otro (Especifique _____)  _____  _____  _____) )  No sabe

	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:
13. ¿Cómo se enteró de este (tratamiento). . . por un miembro de la familia, un(a) amigo(a), medios de comunicación (TV, radio, periódico, revista), un(a) médico(a), un(a) enfermero(a), curanderos(as) u otras fuentes?	Permita múltiples respuestas Familia 1 Amigo(a) 2 Medios de Comunicación 3 Profesional de la salud (especifique) 4 Otro (especifique) 5 No sabe 9	Permita múltiples respuestas Familia 1 Amigo(a) 2 Medios de Comunicación 3 Profesional de la salud (especifique) 4 Otro (especifique) 5 No sabe 9	Permita múltiples respuestas Familia 1 Amigo(a) 2 Medios de Comunicación 3 Profesional de la salud (especifique) 4 Otro (especifique) 5 No sabe 9	Permita múltiples respuestas Familia 1 Amigo(a) 2 Medios de Comunicación 3 Profesional de la salud (especifique) 4 Otro (especifique) 5 No sabe 9
14. ¿Habló con su doctor acerca de este (tratamiento)?	Sí 1 No 2 (PASE al 16a) No sabe 9	Sí 1 No 2 (PASE al 16a) No sabe 9	Sí 1 No 2 (PASE al 16a) No sabe 9	Sí 1 No 2 (PASE al 16a) No sabe 9

	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:
15. ¿Cuál fué la respuesta de su doctor. Le recomendó, estuvo de acuerdo u objetó que probara el (tratamiento) ?	Recomendó 1 Objetó 2 Estuvo de acuerdo 3 No sabe 9	Recomendó 1 Objetó 2 Estuvo de acuerdo 3 No sabe 9	Recomendó 1 Objetó 2 Estuvo de acuerdo 3 No sabe 9	Recomendó 1 Objetó 2 Estuvo de acuerdo 3 No sabe 9
16a. ¿Cuántas veces por día/ semana/mes/año siguió este (tratamiento) ?	____ /día; ____ / semana; ____ / mes; ____ / año No sabe 99	____ /día; ____ / semana; ____ / mes; ____ / año No sabe 99	____ /día; ____ / semana; ____ / mes; ____ / año No sabe 99	____ /día; ____ / semana; ____ / mes; ____ / año No sabe 99

	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:
	_____	_____	_____	_____
16b. ¿Por cuánto tiempo en total siguió Ud. el (tratamiento)?	meses _____ años _____ No sabe 99	meses _____ años _____ No sabe 99	meses _____ años _____ No sabe 99	meses _____ años _____ No sabe 99
17. ¿Está Ud. todavía recibiendo el (tratamiento)?	SÍ 1 (PASE al 19) No 2 No sabe 9	SÍ 1 (PASE al 19) No 2 No sabe 9	SÍ 1 (PASE al 19) No 2 No sabe 9	SÍ 1 (PASE al 19) No 2 No sabe 9

	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:
18. ¿Por qué lo dejó?	1 Una sola sesión 2 Muy costoso 3 Condición no cambió 4 Condición mejoró 5 Condición empeoró Incómoda/efectos dolorosos 6 por el tratamiento 7 Consejo del doctor Otro (especifique) _____ 8 _____ 99 No sabe	1 Una sola sesión 2 Muy costoso 3 Condición no cambió 4 Condición mejoró 5 Condición empeoró Incómoda/efectos dolorosos 6 por el tratamiento 7 Consejo del doctor Otro (especifique) _____ 8 _____ 9 No sabe	1 Una sola sesión 2 Muy costoso 3 Condición no cambió 4 Condición mejoró 5 Condición empeoró Incómoda/efectos dolorosos 6 por el tratamiento 7 Consejo del doctor Otro (especifique) _____ 8 _____ 99 No sabe	1 Una sola sesión 2 Muy costoso 3 Condición no cambió 4 Condición mejoró 5 Condición empeoró Incómoda/efectos dolorosos 6 por el tratamiento 7 Consejo del doctor Otro (especifique) _____ 8 _____ 99 No sabe

	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:
19a. ¿Ud. piensa que este (tratamiento) la ha ayudado?	Sí <input type="checkbox"/> No <input type="checkbox"/> No sabe <input type="checkbox"/> 1 2 9 SI "NO" O "NO SABE", PASE AL 20a.	Sí <input type="checkbox"/> No <input type="checkbox"/> No sabe <input type="checkbox"/> 1 2 9 SI "NO" O "NO SABE", PASE AL 20a.	Sí <input type="checkbox"/> No <input type="checkbox"/> No sabe <input type="checkbox"/> 1 2 9 SI "NO" O "NO SABE", PASE AL 20a.	Sí <input type="checkbox"/> No <input type="checkbox"/> No sabe <input type="checkbox"/> 1 2 9 SI "NO" O "NO SABE", PASE AL 20a.
19b. SI RESPONDIO QUE LA AYUDO:  ¿De qué manera piensa Ud. que la ha ayudado el (tratamiento)? [GRABE PALABRA POR PALABRA]	_____ _____ _____ _____	_____ _____ _____ _____	_____ _____ _____ _____	_____ _____ _____ _____
20a. ¿Le ha hecho daño de alguna manera este (tratamiento)?	Sí <input type="checkbox"/> No <input type="checkbox"/> No sabe <input type="checkbox"/> 1 2 9 SI "NO" O "NO SABE", PASE AL 21.	Sí <input type="checkbox"/> No <input type="checkbox"/> No sabe <input type="checkbox"/> 1 2 9 SI "NO" O "NO SABE", PASE AL 21.	Sí <input type="checkbox"/> No <input type="checkbox"/> No sabe <input type="checkbox"/> 1 2 9 SI "NO" O "NO SABE", PASE AL 21.	Sí <input type="checkbox"/> No <input type="checkbox"/> No sabe <input type="checkbox"/> 1 2 9 SI "NO" O "NO SABE", PASE AL 21.
20b. SI RESPONDIO QUE LE HIZO DAÑO:  ¿De qué manera siente Ud. que le hizo daño este (tratamiento)? [ESCRIBA PALABRA POR PALABRA]	_____ _____ _____ _____	_____ _____ _____ _____	_____ _____ _____ _____	_____ _____ _____ _____

	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:
	_____	_____	_____	TRATAMIENTO: _____
21. ¿Dada esta experiencia, si alguien con cáncer en el seno le preguntara, recomendaría Ud. este tratamiento?	Sí _____ No _____ No sabe _____ 1        2        9	Sí _____ No _____ No sabe _____ 1        2        9	Sí _____ No _____ No sabe _____ 1        2        9	Sí _____ No _____ No sabe _____ 1        2        9
22. ¿Qué distancia (ida y vuelta) y/o cuánto tiempo tenía que viajar cada vez que recibía ( <i>tratamiento</i> )?	distancia (millas) _____ tiempo (minutos) _____ No tenía que viajar 0 No sabe 999	distancia (millas) _____ tiempo (minutos) _____ No tenía que viajar 0 No sabe 999	distancia (millas) _____ tiempo (minutos) _____ No tenía que viajar 0 No sabe 999	distancia (millas) _____ tiempo (minutos) _____ No tenía que viajar 0 No sabe 999
23. ¿Fue todo o parte del costo del (tratamiento) pagado por una compañía de seguros?	Sí, todo (PASE AL 25) 1 Sí, algo 2 No 3 No sabe 9	Sí, todo (PASE AL 25) 1 Sí, algo 2 No 3 No sabe 9	Sí, todo (PASE AL 25) 1 Sí, algo 2 No 3 No sabe 9	Sí, todo (PASE AL 25) 1 Sí, algo 2 No 3 No sabe 9

	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:	TRATAMIENTO:
24a. ¿Cuál fué la cantidad promedio de la que fué responsable de pagar por cada visita?	\$ _____ No sabe 9	\$ _____ No sabe 9	\$ _____ No sabe 9	\$ _____ No sabe 9
24b. ¿Cuál fué la cantidad total de la que fué responsable de pagar por el (tratamiento)s?	\$ _____ No sabe 9	\$ _____ No sabe 9	\$ _____ No sabe 9	\$ _____ No sabe 9
25. ¿Siguió o tuvo Ud. este (tratamiento) 2 años antes del diagnóstico de cáncer en el seno?	Sí _____ No _____ 1 2 9	Sí _____ No _____ 1 2 9	Sí _____ No _____ 1 2 9	Sí _____ No _____ 1 2 9

26. Ahora le voy a leer una lista de enfermedades y síntomas. ¿Por favor dígame si Ud. tuvo alguna de estas enfermedades y/o síntomas en los dos años antes del diagnóstico de cáncer en el seno? Por favor conteste si o no.

(LEA TODAS LAS CATEGORIAS)		<u>Sí</u>	<u>No</u>	<u>No sabe</u>
a.	Tumor o cáncer (además de cáncer en el seno)	1	2	9
b.	Problemas digestivos	1	2	9
c.	Problemas de la vejiga o el sistema urinario	1	2	9
d.	Problemas ginecológicos o menstruales	1	2	9
e.	Problemas de la piel	1	2	9
f.	Obesidad	1	2	9
g.	Depresión	1	2	9
h.	Insomnio	1	2	9
i.	Virus de Inmunodeficiencia Humana	1	2	9
j.	Artritis	1	2	9
k.	Problemas de la espalda	1	2	9
l.	Dolores de cabeza	1	2	9
m.	Otro (Si sí, especifique _____)	1	2	9

**Ahora me gustaría hacerle algunas preguntas acerca de su historia familiar.**

27. ¿Alguna vez sufrió su madre de cáncer en el seno?

Sí	1
No	2
No sabe	9

28. ¿Cuántas hermanas, incluyendo medias-hermanas, tiene? \_\_\_\_\_

**(SI NINGUNA, PASE A LA PREGUNTA 30)**

29. ¿Alguna de ellas/ella ha tenido alguna vez cáncer en el seno?

Sí (Especifique cuántas _____)	1
No	2
No sabe	9

30. ¿Cuántas hijas tiene? \_\_\_\_\_

(SI NINGUNA, PASE A LA PREGUNTA 32)

31. ¿Alguna de ellas o ella ha tenido alguna vez cáncer en el seno?

Sí (Especifique cuántas _____)	1
No	2
No sabe	9

32. ¿Alguna de sus abuelas ha tenido alguna vez cáncer en el seno?

Sí (Especifique paterna/materna/ambas _____)	1
No	2
No sabe	9

33. ¿Ha tenido alguna vez alguna de sus mejores amigas cáncer en el seno?

Sí	1
No	2
No sabe	9

(SI RESPONDE SI PARA CUALQUIERA DE LOS FAMILIARES Y/O AMIGAS, PREGUNTE LA 34; DE OTRA MANERA PASE A 35)

34. ¿El hecho de que su(s) familiar(es) y/o amiga(s) tuviera cáncer en el seno influyó en el tratamiento que Ud. escogió?

Sí	1
No	2
No sabe	9

35. ¿Antes de padecer de cáncer en el seno, participó en alguno de los siguientes grupos por lo menos una vez al mes?

(LEA TODAS LAS CATEGORIAS)

	<u>Sí</u>	<u>No</u>	<u>No sabe</u>
Grupo Religioso	1	2	9
Grupo social o recreacional no religioso	1	2	9
Grupo gremial, comercial o asociación profesional	1	2	9
Grupo que se preocupa por los niños, tales como PTA o Boy Scouts	1	2	9
Grupo para mejora de la comunidad, de caridad o servicio	1	2	9
Cualquier otro grupo _____	1	2	9

36. ¿Antes de que le fuera diagnosticado cáncer en el seno, cuán satisfecha estaba Ud. con su vida personal? ¿Diría Ud. que muy satisfecha, generalmente satisfecha, de alguna manera satisfecha, generalmente descontenta o muy descontenta?

Muy satisfecha	1
Generalmente satisfecha	2
De alguna manera satisfecha	3
Generalmente descontenta	4
Muy descontenta	5
No sabe	9

37. En términos de su satisfacción con su vida personal antes del diagnóstico de cáncer en el seno, por favor evalúe lo siguiente como malo, regular, bueno, muy bueno o excelente:

(LEA TODAS LAS CATEGORIAS)

	<u>malo</u>	<u>regular</u>	<u>bueno</u>	<u>muy bueno</u>	<u>excelente</u>
El grado de unión y cohesión que tenía ya sea con su familia o amigos(as)	1	2	3	4	5
El apoyo y comprensión que se daban entre sí	1	2	3	4	5
Lo mucho que hablaban acerca de las cosas	1	2	3	4	5

38. ¿Antes de éste diagnóstico de cáncer en el seno, cuánto disfrutaba generalmente las cosas que hacía?. Diría que todo el tiempo, usualmente, algunas veces, poco tiempo o nunca?

Todo el tiempo	1
Usualmente	2
Algunas veces	3
Poco tiempo	4
Nunca	5
No sabe	9

39. Desde que supo que tenía cáncer en el seno, ha comenzado, ha parado, ha continuado haciendo o no ha continuado haciendo cada una de estas cosas:

(LEA TODAS LAS CATEGORIAS) comenzado parado continuado haciendo no ha continuado haciendo

Ejercicios	1	2	3	4
Fumar	1	2	3	4
Ingerir alcohol	1	2	3	4
Consejería de alguna clase	1	2	3	4
Asistir a grupos de apoyo	1	2	3	4

**Ahora me gustaría hacerle algunas preguntas acerca de su historia menstrual y sus antecedentes.**

40. ¿Qué edad tenía Ud. cuando le tuvo su **primer** período menstrual?  
\_\_\_\_\_ años

41. ¿Ha llegado Ud. a su menopausia, la cual también se conoce como "el cambio de vida"?

Sí	1
No	2 (PASE AL 43)
No sabe	9

42. ¿Qué edad tenía Ud. cuando tuvo su **último** período menstrual?  
\_\_\_\_\_ años

43. ¿Cuántas veces ha estado Ud. embarazada? Por favor incluya **todos** los embarazos, nacimientos normales, muertes del feto, pérdidas, embarazos ectópicos y abortos.

\_\_\_\_\_

44. ¿En qué país nació?

U.S.A.	1 (PASE AL 46)
Otro _____	2
No sabe	9

45. ¿Cuántos años ha vivido en U.S.A.?

\_\_\_\_\_  
(años)

46. ¿Cuánto tiempo ha vivido en San Francisco?

\_\_\_\_\_  
(años)

47. Cuando le diagnosticaron cáncer en el seno

a. ¿Estaba Ud. viviendo sola?

Sí	1
No	2
No sabe	9

47b. ¿Cuál era su estado civil entonces?

Casada o viviendo con alguien	1
Casada anteriormete, ahora soltera	2
Nunca se ha casado	3
No sabe	9

47c. ¿Cuál era su religión cuando le diagnosticaron cáncer en el seno?

Protestante	1
Católica	2
Judía	3
Islámica/Musulmana	4
Budista	5
Culto Ancestral	6
Otra _____	7
Combinación _____	8
No tiene preferencia	9
Ninguna	10

d. ¿Cerca del momento cuando le diagnosticaron cáncer en el seno qué clase de seguro médico o cobertura tenía, si alguna, por ejemplo Kaiser, Health Net, Take Care, Blue Cross, Blue Shield, MediCal o MediCare?

De Gobierno (MediCal, MediCare, Administración de Veteranos)	1
Seguro Privado o HMO _____	2
Ninguno	3
No sabe	9

48. ¿Hasta qué grado llegó en la escuela, no incluya clases de inglés y entrenamiento para el trabajo?

Ninguno	1
Primaria	2
Secundaria Básica	3
Secundaria	4
Algo de Universidad	5
Grado Universitario	6
Escuela de Graduados	7
No sabe	9

Finalmente, tengo una pregunta acerca del ingreso en su hogar. Nosotros entendemos que puede ser difícil calcular el ingreso. Sin embargo, esta información nos va a ayudar a entender mejor los factores que influyen en la escogencia de tratamientos en nuestra comunidad. Esta información, lo mismo que todos los otros datos, será estrictamente confidencial.

49. ¿Durante el pasado año (199\_\_\_), cuántas personas dependieron del ingreso total en su hogar?

\_\_\_\_\_

50. Por favor calcule el ingreso total aproximado en su hogar, antes de la deducción de impuestos, en el último año, 199\_\_\_. Por favor incluya dinero recibido por su salario, pagos de seguro social, beneficios por pensión de retiro, beneficios por desempleo, programas de ayuda social, etc. Diría que el ingreso fué: (LEA TODAS LAS CATEGORIAS)

Menos de \$10,000	1
\$10,001-\$20,000	2
\$20,001-\$40,000	3
\$40,001-\$60,000	4
\$60,001 o más	5
Se negó a contestar	8
No sabe	9

51. ¿Tiene Ud. dos personas amigas o familiares, a quienes nosotros podamos contactar en caso de que Ud. se mude y nosotros necesitemos ponernos en contacto con Ud.? ¿Cuáles son sus nombres y números de teléfono?

Nombre

Número de teléfono

1) \_\_\_\_\_

2) \_\_\_\_\_

52. Esas son todas las preguntas que tengo para Ud. ¿Tiene algún comentario o pregunta?

\_\_\_\_\_

\_\_\_\_\_

53. (NO LO LEA) ¿Pidió esta persona los resultados?

Sí  
No

1  
2

**MUCHISIMAS GRACIAS POR SU PARTICIPACION**

## Appendix II

**M.D. Letter**

, 1995

, M.D.  
Address  
San Francisco, CA 941

Dear Dr. :

We are conducting an epidemiologic study to determine the use of alternative and conventional therapies by breast cancer patients. This population-based study includes women in four ethnic groups living in San Francisco County who were newly diagnosed with breast cancer during the period 1990 to 1992. Participation involves a single, 30-minute telephone interview concerning use of therapies as well as potential influences on use, such as age, acculturation, education, income, religion, and social support.

We obtain the names of patients from the California Tumor Registry, the agency mandated by the State to collect tumor data. Prior to contacting patients, we routinely ask their physicians about any medical contraindications to approaching them. You were listed as the physician of record for \_\_\_\_\_. If you feel there are medical contraindications to our making initial contact with her by letter, please call me at (415) 476-0743. If I do not hear from you within two weeks, I will assume that there are no contraindications to our approaching this patient. We will then send a letter explaining our study to her.

Our multi-lingual trained interviewers are sensitive to challenges faced by cancer patients. They will conduct the interview at a time convenient to each subject. All records will be handled as confidentially as possible. No patient or physician will be identified by name to anyone outside our research unit. A subject may refuse to participate at any time. We expect that most subjects will be glad to contribute to cancer research by helping with our study.

I greatly appreciate your assistance. Please feel free to call me if you would like any further information about this study.

Sincerely,

Marion Lee, Ph.D.  
Principal Investigator  
Associate Professor  
of Epidemiology and Biostatistics

**M. D. Letter (Deceased Patient)**

August , 1995

, M.D.  
Address  
City

Dear Dr. \_\_\_\_\_:

We are conducting an epidemiologic study to determine the use of alternative and conventional therapies by breast cancer patients. This population-based study includes women in four ethnic groups living in San Francisco County who were newly diagnosed with breast cancer during the period 1990 to 1992. Participation involves a single, 30-minute telephone interview concerning use of therapies as well as potential influences on use, such as age, acculturation, education, income, religion, and social support.

We obtain the names of patients from the California Tumor Registry, the agency mandated by the State to collect tumor data. Prior to contacting patients or their next of kin (if deceased), we routinely ask their physicians about any medical contraindications to approaching them. You were listed as the physician of record for \_\_\_\_\_. If you feel there are any medical contraindications to our making initial contact with her next of kin by letter, please call me at (415) 476-0743. If I do not hear from you within two weeks, I will assume that we can approach this patient's relative. We will then send a letter explaining our study for proxy interview.

Our multi-lingual trained interviewers are sensitive to challenges faced by cancer patients and their family. They will conduct the interview at a time convenient to each subject. All records will be handled as confidentially as possible. No patient or physician will be identified by name to anyone outside our research unit. A subject may refuse to participate at any time. We expect that most subjects will be glad to contribute to cancer research by helping with our study.

I greatly appreciate your assistance. Please feel free to call me if you would like any further information about this study.

Sincerely,

Marion Lee, Ph.D.  
Principal Investigator  
Associate Professor  
of Epidemiology and Biostatistics

## Consent To Be A Research Subject

## A. Purpose and Background

Dr. Marion Lee and her colleagues from the University of California are conducting a study to learn the prevalence of use of breast cancer therapies including conventional, alternative and unconventional treatments among 400 patients diagnosed with breast cancer representing four ethnic groups in San Francisco. The study was funded by U.S. Army Medical Research and Material Command. The study will also determine if factors such as age, ethnicity, acculturation, income, education, religion, social support and some breast cancer prognostic factors on the use of different therapies.

## B. Procedures

I will receive a letter explaining the study and will be asked to participate in a 30 minutes telephone interview conducted by the language of my choice.

## C. Risk and Discomfort

No sensitive information will be solicited and no health risks are involved.

## D. Benefits

There is no direct benefit for my participation. However results from this study will benefit breast cancer patients in general by providing important data for the use and outcome of alternative therapies.

## E. Cost

There will be no cost to me for my participation.

## F. Confidentiality

My research records will be handled as confidential as possible. All records will be coded and kept in locked files so that only study investigators have access to them. No individual identification will be used in any reports or publications. Representatives from the U.S. Army Medical Research And Material Command can review my research records as part of their responsibility to protect human subjects in research.

## G. Consent for Participation is Voluntary

I Have the right to decline to participate or to withdraw at any point in this study without any jeopardy. If I wish to participate, I should sign below and I have been provided a copy of this consent form to keep. I am authorized all necessary medical care for injury or disease which is the proximate result of my participation in this research. The U.S. Army requires that UCSF provide such medical care when conducting research with private citizens. Other than medical care that may be provided, I will not receive any compensation for my participation in this research study; however, I should understand that this is not a waiver or release of my legal rights.

PLEASE INITIAL AND DATE THIS PAGE OF THE CONSENT FORM TO INDICATE YOU HAVE READ AND UNDERSTOOD. Subject \_\_\_\_\_, Date \_\_\_\_\_

Witness \_\_\_\_\_, Date \_\_\_\_\_

CHOICES OF BREAST CANCER THERAPIES IN FOUR ETHNIC GROUPS 9/94

Consent to Be a Research Subject (continued)

H. Questions

This study has been explained to me and my questions are answered. If I have any other question about the study, I may call Dr. Lee at 476-0743. For information about being a research subject, I may call the office of the committee on Human Research at UCSF, 476-1814.

\_\_\_\_\_  
(Subject's Signature)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Subject's printed name)

\_\_\_\_\_  
(Subject's permanent address)

\_\_\_\_\_  
(Witness's signature)

\_\_\_\_\_  
(Date)

\_\_\_\_\_  
(Witness's printed name)

H6442-09964-01

## Contact Letter for Patient

August , 1995

Name  
Address  
City  
Telephone

Dear Ms. \_\_\_\_\_:

We would like your help with a research study being conducted by the University of California, San Francisco. The purpose of this study is to increase our knowledge of which treatments and therapies are used by women who have had breast cancer. Therefore, we are interviewing women who were diagnosed in San Francisco with breast cancer during the time period January 1990 through December 1992. We obtained your name from the California Tumor Registry. Your physician, \_\_\_\_\_, M.D., has been contacted and agreed for us to approach you.

Your participation in this study would be greatly appreciated. It would consist of a single telephone interview lasting about twenty minutes, concerning your choice of therapies, feelings about health care, health status, ethnicity, education, and family and friend support. The information you provide will be kept as confidential as much as possible, and your name will not appear in any report or publication resulting from this study. Your participation is entirely voluntary. The interview will take place at a time convenient for you, and you may refuse to answer any question or stop the interview at any time.

We hope you will help us with this study, as each person's experience adds valuable information in the effort to provide the most effective cancer therapies.

Within the next week, one of our experienced interviewers will call to see if you are willing to participate in the study, and if so, to interview you then if the time is convenient, or to arrange another time for the interview. Please feel free to ask her any questions, or you may call me collect. **Also, if you do not want to participate, please call me at (415) 476-0743 and we will not contact you. If your current telephone number differs from the one listed above, we would appreciate it if you would call our office to give us the number where you may be reached.**

You may talk with someone regarding you as a research subject at the Committee on Human Research by calling (415) 476-1814. Thank you very much for your attention to this letter, We look forward to speaking with you.

Sincerely,

Marion Lee, Ph.D.  
Principal Investigator  
Associate Professor of Epidemiology and Biostatistics

您好。

這封信是邀請您考慮一項由加州大學舊金山醫學院舉辦的研究項目。這項研究的目的是使我們能夠更加了解患乳癌的婦女採用哪些治療方法。我們會訪問一些曾在一九九零年一月至一九九二年十二月期間內在三藩市曾被診斷出有乳癌的婦女。我們是從加州腫瘤研究所得到您的名單的。我們已經跟您的醫生 \_\_\_\_\_ 聯絡過，他也同意我們跟您接觸。

這項研究將會包括一個大約二十分鐘的電話訪問。這個訪問是關於您選擇了哪些治療方法、您對健康護理的感覺、您的健康情況、以及您的教育程度、家庭和朋友對您的支持等等問題。我們將會把您給我們的資料儘量保密，您的名字將不會出現在這項研究所發表的任何報告或出版物中。我們將會在一個方便您的時間來訪問您，而且您可以拒絕回答任何問題或者是在任何時間終止訪問。我們將會十分感激您對這項研究的考慮。

在下一個星期，我們一位有經驗的訪問員將會打電話給您，問您是否願意參加這項研究。如果您願意而時間又方便的話，她就會即時訪問您。否則，她會跟您另約時間做訪問。請隨便問她任何問題，或者您可以打 (415) 476-0743 給我。同時，如果您現在的電話號碼跟印在上面的不同，請您打電話到我們的辦公室告訴我們您現在的電話號碼。

您可以打 (415) 476-1814 到人類研究委員會查詢有關您作為一個研究對象的事情。十分謝謝您看這封信。我們期望著跟您談話。

我們希望您能考慮這一項研究，因為每個人的經驗都能夠為我們提供最有效的癌症治療方法加添寶貴的資料。

如果您選擇不參加這項研究的話，請打 (415) 476-0743 告訴我們，我們便不會打電話給您，謝謝。

Marion Lee, Ph.D.  
Principal Investigator  
Associate Professor  
of Epidemiology and Biostatistics

謹上

## Proxy Letter

August , 1995

Family of \_\_\_\_\_  
Address \_\_\_\_\_  
City \_\_\_\_\_  
Telephone \_\_\_\_\_

Dear Family of \_\_\_\_\_:

We would like your help with a research study being conducted by the University of California, San Francisco. The purpose of this study is to increase our knowledge of which treatments and therapies are used by women who have had breast cancer. Therefore, we are interviewing women who were diagnosed in San Francisco with breast cancer during the time period January 1990 through December 1992. We obtained your name from the California Tumor Registry.

\_\_\_\_\_ 's physician, \_\_\_\_\_, M. D., has been contacted and agreed for us to approach you.

Your participation in this study would be greatly appreciated. It would consist of a single telephone interview lasting about twenty minutes, concerning your choice of therapies, feelings about health care, health status, ethnicity, education, and family and friend support. The information you provide will be kept as confidential as much as possible, and your name will not appear in any report or publication resulting from this study. Your participation is entirely voluntary. The interview will take place at a time convenient for you, and you may refuse to answer any question or stop the interview at any time.

We hope you will help us with this study, as each person's experience adds valuable information in the effort to provide the most effective cancer therapies.

Within the next week, one of our experienced interviewers will call to see if you are willing to participate in the study, and if so, to interview you then if the time is convenient, or to arrange another time for the interview. Please feel free to ask her any questions, or you may call me collect. **Also, if you do not want to participate, please call me at (415) 476-0743 and we will not contact you. If your current telephone number differs from the one listed above, we would appreciate it if you would call our office to give us the number where you may be reached.**

You may talk with someone regarding you as a research subject at the Committee on Human Research by calling (415) 476-1814. Thank you very much for your attention to this letter, We look forward to speaking with you.

Sincerely,

Marion Lee, Ph.D.  
Principal Investigator  
Associate Professor of Epidemiology and Biostatistics

## 致親友書

請參閱我們  
的逝世何能謹致慰問之意。這封信是邀請您  
考慮一項由加州大學舊金山醫學院舉辦的研究項目。這項研究的目的是  
使我們能夠更加了解患乳癌的婦女採用哪一些治療方法。所以，我們  
都希望問您一些關於  
的問題。

因為您是  
的親人，您在這研究的考慮將會對我們有  
極大的幫助。這項研究將會包括一個大約二十分鐘的電話訪問。這  
個訪問是關於  
選擇了哪一些治療方法，家庭和朋友對她的  
支持和她教育程度等等的問題。我們會把您給我們的資料儘量  
保密，您和她的名字都將不會出現在這項研究所發表的任何報告  
或出版物中。您的考慮是完全自願的。我們將會在一個方便您的  
時間來訪問您，而且您可以拒絕回答任何問題或者是在任何時間終止  
訪問。我們已經跟病人的醫生  
聯絡過，他亦同意  
我們跟您接觸。

在下一個星期，我們一位有經驗的訪問員將會打電話給您，問您是否  
願意參加這項研究。如果您親友的時間又方便的話，她也會即  
時訪問您。否則，她會跟您另約時間做訪問。請隨便問她  
任何問題，或者您可以打(415) 436-1814給我。同時，如果您現  
在的電話號碼跟印在上面的不同，請您打電話到我們的辦公室  
告訴我們您現在的電話號碼。

我們希望您能考慮這一項研究，因為每一個癌症患者的經驗都能  
夠為我們提供最有效的癌症治療方法加添真實的資料。如果  
您不能夠參加，我們希望能夠訪問另外一位可以告訴我們關於  
事情的親戚或者朋友。

您可以打(415) 436-1814到人類研究委員會查詢有關您作為一個  
研究對象的事情。十分謝謝您看這封信，我們期望着  
跟您談話。

Sincerely,

Marion Lee, Ph.D.  
Principal Investigator

## Carta para contactar a la paciente

August , 1995

Name  
Address  
City  
Telephone

Querida Sra./Srta. \_\_\_\_\_:

Nos gustaría que nos ayudara con un estudio de investigación dirigido por la Universidad de California, San Francisco. El propósito de este estudio es aumentar nuestro conocimiento sobre qué tratamientos y terapias son usados por mujeres quienes han tenido cáncer en el seno. Por lo tanto, estamos entrevistando mujeres a quienes les han diagnosticado cáncer en el seno en San Francisco durante el período de tiempo entre Enero de 1990 y Diciembre de 1992. Nosotros obtuvimos su nombre en el California Tumor Registry. Su doctor, \_\_\_\_\_, M.D., ha sido contactado y estuvo de acuerdo con que nosotros nos comunicáramos con Ud.

Su participación en este estudio sería altamente agradecida. Esta consistiría de una sola entrevista telefónica de una duración de aproximadamente veinte minutos relacionada con su preferencia sobre terapias, sus sentimientos acerca del cuidado de la salud, estado de la salud, origen étnico, educación y apoyo de la familia y los amigos. La información que nos proporcione se mantendrá tan confidencial como sea posible y su nombre no va a aparecer en ningún reporte o publicación que resulte de este estudio. Su participación es completamente voluntaria. La entrevista tomará lugar a una hora que a Ud. le convenga y Ud. puede rehusarse a contestar cualquier pregunta o parar la entrevista en cualquier momento.

Nosotros esperamos que nos ayude con este estudio, ya que la experiencia de cada persona añade información valiosa en el esfuerzo de proporcionar las terapias más efectiva para combatir el cáncer.

La próxima semana, una de nuestras experimentadas entrevistadoras la va a llamar para ver si Ud. está dispuesta a participar en el estudio y, si Ud. lo está, la entrevistará en ese momento si la hora es conveniente para Ud. , o acordarán en otra hora para la entrevista. Por favor no deje de hacerle cualquier pregunta que tenga o también Ud. puede llamarme sin cargo alguno para Ud. (collect). También, **si usted no quiere participar, por favor llámeme al (415) 476-0743 y no le llamaremos. Si su número de teléfono es diferente del que aparece en la parte de arriba de esta carta, le agradeceríamos que llamara a nuestra oficina para que nos dé el número en el que la podamos contactar.**

Ud. puede hablar con alguien en relación con su participación como sujeto de investigación, en el Comité de Investigaciones Humanas llamando al (415) 476-1814. Muchas gracias por su atención a esta carta y esperamos hablar pronto con Ud.

Sinceramente,

Marion Lee, Ph.D.  
Investigador Principal  
Profesor Asociado de  
Epidemiología y Bioestadísticas

### **Appendix III**

# **INTERVIEWER'S TRAINING MANUAL CHOICES OF BREAST CANCER TREATMENTS IN FOUR ETHNIC GROUPS**

## **I. OVERVIEW OF THE STUDY**

### **A. Background**

The San Francisco Bay Area is not only rich in ethnic and cultural diversity but also is at the forefront of alternative medical practices. Yet, reliable and comparable data on use and choices of cancer therapies in the four ethnic populations have not been developed. This study proposes to systematically determine the prevalence of utilization of conventional and unconventional breast cancer treatments through telephone interviews with approximately 400 breast cancer patients diagnosed between 1990 and 1992 representative of four ethnic groups (Whites, Blacks, Hispanics, and Chinese-Americans) in San Francisco. Our long range goal is to assess outcomes including cost, quality of life, recurrence and survival among breast cancer patients in the four ethnic groups.

### **B. Objectives**

1. To determine the types of conventional and unconventional therapies used by women in the four different ethnic groups in San Francisco who were diagnosed with breast cancer between 1990 and 1992.
2. To determine the prevalence of use of conventional and unconventional cancer therapies alone or in combinations.
3. To assess the frequency and length of use of various medical care alternatives before and after cancer diagnosis confirmation.

4. To determine the influences, if any, of ethnicity, nativity (foreign born vs. US born), length in the US, acculturation, family income, education, religion, social support, health insurance status, first degree family history of breast cancer, age at diagnosis, on the use of different therapies.

**C. Number of interviews to be completed**

We will conduct a population-based cross-sectional telephone survey of White, Black Hispanic, and Chinese-American breast cancer patients or their proxies. Approximately a total of 100 complete interviews from each ethnic group is expected. Because of the limited number of subjects in the Black, Hispanic, and Chinese groups, effort to increase participation is highly needed.

**D. Projected time-line for data collection**

We plan to begin interviewing from March 1, 1995 and expect to complete the interviews by December, 1995.

**E. Case Selection**

Eligible women will include those who were (1) newly diagnosed with primary breast cancer, either carcinoma-in-situ or invasive between January 1990 and December 1992; (2) identified on the tumor registry abstract form as non-Hispanic Whites, Hispanics, Blacks or Chinese; (3) living in San Francisco at diagnosis. Cases will be identified through the tumor registry of Northern California Cancer Center which is part of the Surveillance, Epidemiology and End Results (SEER) program.

## **II. ADMINISTRATION OF THE QUESTIONNAIRE**

### **A. Reading and asking the questions**

You should remain neutral and objective during the interviews. All the questions should be read and asked exactly as worded, in order to assure reliability, no matter who asks the questions. If the questions are not asked identically to each respondent, the answers to a given question would not be comparable, because each respondent may interpret the question differently; therefore, there should not be any paraphrasing or rewording of the questions.

All the questions should be read in a natural manner. It is always a good idea to practice reading all the questions until they sound natural to the respondents. Always follow the sequence of the questions. Read the questions slowly. If the question is not understood, repeat the question exactly as stated. Do not try to rephrase the question in order to make it more understandable to the respondent.

### **B. Instructions**

All the instructions are CAPITALIZED; AND THEY ARE NOT TO BE READ to the respondents.

All the response categories are not to be read unless specified in the instructions.

### **C. Adminstrating the Questionnaire**

#### **INTRODUCTION**

Request to speak with the designated respondent. If the person on the phone is the designated respondent/when the designated respondent comes to the phone, confirm her name, introduce yourself ( READ THE TELEPHONE CONSENT SCRIPT) and proceed to Q1. If the respondent is not available, call back some other time. Refer all the research questions to Dr. Marion Lee at (415) 476-0743.

- \* If a proxy is interviewed, use "she" or "her" instead of "you" and "your".
- \* Use 9's to designate DK or Do Not Recall.
- \* **USE A PENSIL TO RECORD THE ANSWERS.**

Q1 Confirm the eligibility of the respondent. If the respondent has never been diagnosed with breast cancer, thank her and terminate the interview.

Q2 Self-explanatory. Record the month and the year of the breast cancer diagnosis.

Q3 Self-explanatory.

Q4/Q5  
Self-explanatory. **READ ALL RESPONSE CATEGORIES.**

Q6 **READ ALL RESPONSE CATEGORIES.** If the response is "By yourself", skip to Q7b. Otherwise, go to Q7a.

Q7a If the response is "No", skip to Q8. Otherwise, go to Q7b and record verbatim.

Q7b Record what the respondent says.

Q7c Record either the number of days (if less than one month) or the number of months (if one month or more).

Q8 Circle ONE response (YES/NO/DK) for EVERY question.  
**READ ALL RESPONSE CATEGORIES.**

8f If the response is "Yes", record the name of the dietary therapy.

Q9 If the response is "Yes", record the name of the treatment(s) and/or therapy(ies).

## Q10 - Q25

- \* Check the answers in Q8.
- \* Ask the question **vertically** (from top to bottom) for all the treatments and/or therapies that the respondent says "yes" to in Q8.
- \* Conventional treatments are listed on pages 4 to 7.  
All other treatments/therapies are listed on pages 8 to 15 (use additional pages if there are more than 4 unconventional treatments/therapies).

### Surgery/Reconstructive Surgery/Chemotherapy/Radiation

#### 10a FOR SURGERY:

Ask question a through d.

If the response is "Yes", ask "How many" and record the number of times receiving the particular surgery.

If the respondent has had more than one kind of the surgeries, choose the most severe type of surgery and ask the rest of the questions base on the most sever type of surgery.

The severity of the surgeries are in ascending order. In other words, Radical mastectomy is more severe than Modified radical mastectomy, MRM is more severe than Lumpectomy, and Lumpectomy is more severe than Biopsy.

#### FOR RECONSTRUCTIVE SURGERY

If the response is "No", skip to the next treatment that the respondent has had. Otherwise, ask "When" and record the date of receiving reconstructive surgery.

**10b DO NOT ASK THIS QUESTION FOR SURGERY AND  
RECONSTRUCTIVE SURGERY.**

**FOR CHEMOTHERAPY AND RADIATION, record the number  
days (if less than a month), the number of months (if less than  
a year), or the number of years.**

**Q19a If the response is "No" or "Dk", skip to Q20a. Otherwise, go  
to Q19b.**

**Q19b If the response in Q19a is "Yes", ask this question and record  
verbatim.**

**Q20a If the response is "No" or "Dk", skip to Q21. Otherwise, go  
to Q20b.**

**Q20b If the response in Q20a is "Yes", ask this question and record  
verbatim.**

**Q21 Self-explanatory.**

**Q22 FOR SURGERY AND RECONSTRUCTIVE SURGERY, READ:  
"How far in round trip distance and/or total time did you have  
to travel to receive (treatment)?"**

**FOR CHEMOTHERAPY AND RADIATION, READ:  
"How far in round trip distance and/or total time did you have  
to travel EACH TIME to receive (treatment)?"  
Record the number of miles and/or the number of minutes.**

**Q23 If the response is "Yes", skip Q24b and go to the next  
treatment. Otherwise, ask Q24b.**

**Q24b Record the TOTAL amount of payment that the subject is  
responsible for and go to the next treatment.**

**Other treatments/therapies**

**Record the name of each treatment/therapy which the respondent has had before asking the questions.**

**Q11 Self-explanatory. Record verbatim.**

**Q12 If the response is "By others", ask the respondent to specify the person who provided the treatment.**

**Q13 ALLOW MULTIPLE ANSWERS.**

**Ask the respondent to specify the source(s) if the response(s) is/are "Health professional" and/or "Other".**

**Q14 Self-explanatory. If the response is "No", skip to Q16a. Otherwise, go to Q15.**

**Q15/Q16a/Q16b**

**Self-explanatory.**

**Q17 If the response is "Yes", skip to Q 19. Otherwise , go to Q18.**

**Q18 If the response does not fit into the 7 response categories, record the reason for stop using the treatment next to "Other".**

**Q19 to Q23**

**SEE INSTRUCTIONS FOR Surgery/Reconstructive surgery/  
Chemotherapy/Radiation.**

**Q24a Record the AVERAGE amount of payment for EACH VISIT.**

**Q24b Record the TOTAL amount of payment for the treatment.**

**Q25 Self-explanatory. After asking this question, go to the next treatment until all "yes" from Q8 are covered.**

- Q26** Circle ONE response (YES/NO/DK) for EVERY question.  
For Q26m, if the response is "Yes", record the name(s) of the condition(s) or symptom(s).
- Q27** Self-explanatory.
- Q28** If the response is "None", put down "0" and skip to Q30.  
Otherwise, go to Q29.
- Q29** Self-explanatory. If the response is "Yes", record the number of sisters who had breast cancer.
- Q30** If the response is "None", put down "0" and skip to Q32.  
Otherwise, go to Q31.
- Q31** Self-explanatory. If the response is "Yes", record the number of daughters who had breast cancer.
- Q32** Self-explanatory. If the response is "Yes", specify whether it was the paternal, maternal, or both grandmothers who had breast cancer.
- Q33** Self-explanatory.
- Q34** Ask this question ONLY IF the response is "Yes" in Q27 and/or Q29 and/or Q31 and/or Q32 and/or Q33. Otherwise, skip to Q35.
- Q35** **READ ALL RESPONSE CATEGORIES.**  
Circle ONE response (YES/NO/DK) for EVERY question. If there respondent had participated in any other groups, record the name(s) of the group(s).
- Q36** Self-explanatory.

**Q37 READ ALL RESPONSE CATEGORIES.**

Circle ONE response (Poor/Fair/Good/Very Good/Excellent) for EVERY question.

Q38 Self-explanatory.

**Q39 READ ALL RESPONSE CATEGORIES.**

Circle ONE response (Started/Stopped/Continued to do/Continued not to do) for EVERY question.

Q40 Record the age when respondent had her FIRST menstrual period.

Q41 If the response is "No", skip to Q43. Otherwise, go to Q42.

Q42 Record the age when respondent had her LAST menstrual period.

Q43 Record the number of times that the respondent have been pregnant.

Q44 If the respondent were born in U.S.A., skip to Q46. Otherwise, go to Q45.

Q45/Q46/Q47a/Q47b

Self-explanatory.

Q47c If the response is "Other" or "Combination", record the name(s) of the religion(s).

Q47d If the respondent had private insurance or HMO, record the name of the health care coverage/health insurance.

Q48 Self-explanatory.

Q49 READ: "During the last year **1994**, how many people depended on your total household income?"  
Record the number of dependents, including respondent herself.

Q50 Last year = 1994. **READ ALL RESPONSE CATEGORIES.**

Q51 Record the names and the phone numbers of two close friends or relatives of the respondents.

Q52 Record verbatim.

Q53 **DO NOT READ THIS QUESTION TO THE RESPONDENT!**

*THANK THE RESPONDENT FOR HER TIME AND HER PARTICIPATION AND END THE INTERVIEW.*